



**Healthy London
Partnership**



North West London CYP asthma meeting

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02

Outcome Measures for preschool children with recurrent wheeze

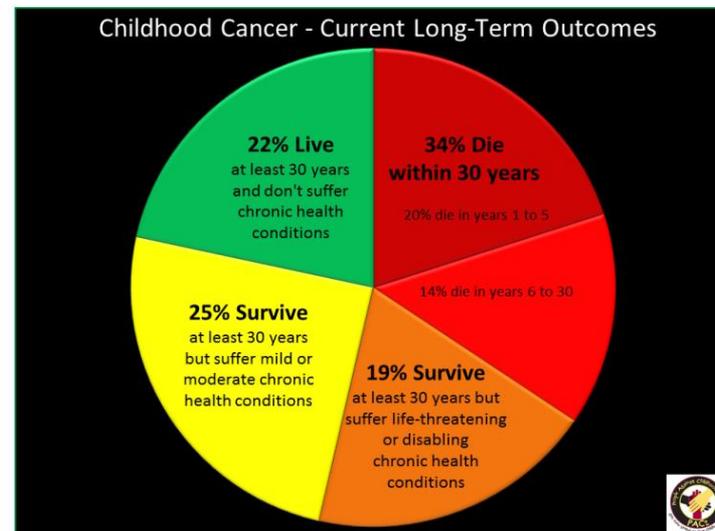
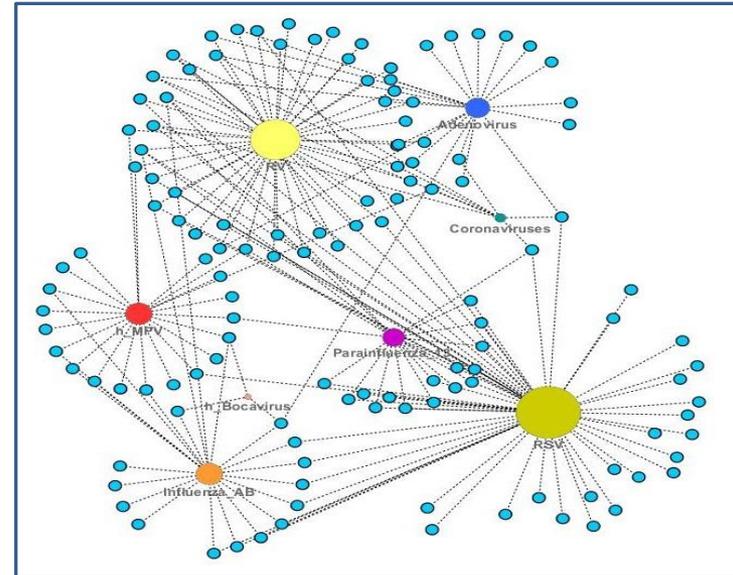
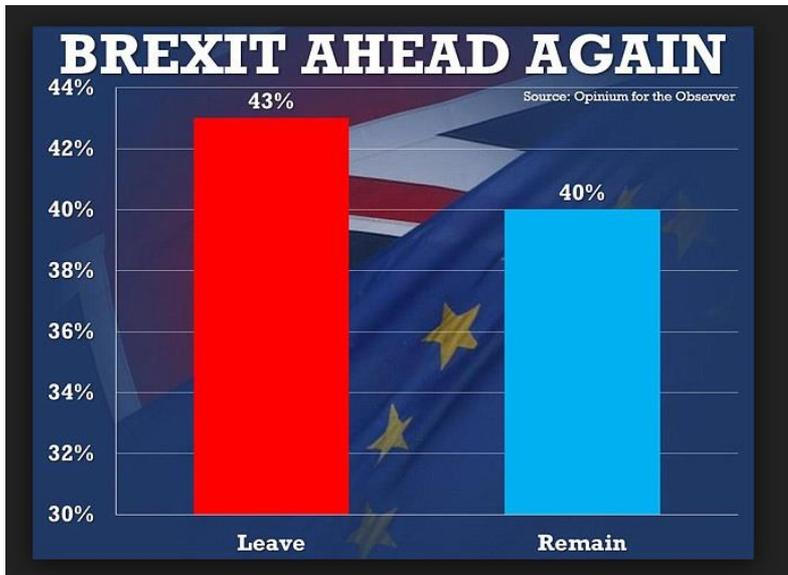
Heidi Makrinioti, MD, PhD

ST3 in Paediatrics

What is an outcome

- **result**
- end **result**
- **consequence**
- net **result** **synonym**
- upshot
- effect
- aftermath
- **conclusion**

Outcomes



Outcomes in child health



Outcomes in child health

“Today I’ve really been struggling with my asthma and extremely breathless feeling awful as though I’ve had a herd of elephants taking up my chest residence – I feel hopeless Hope you are all having a good night sleep”

“ I did not go kickboxing tonight because where I do it is chilly – I am more miserable than I should because I cannot exercise anything like I used to”

“There’s a family get together this weekend and my lungs have decided that this week they would become very troublesome, hence me missing out on the celebration, it’s so unfair, sometimes I hate being asthmatic. Sorry for the rant”

what doctors don't know about their patients

“Today I've really been struggling with my asthma and extremely breathless feeling awful as though I've had a herd of elephants taking up my chest residence – I feel hopeless Hope you are all having a good night sleep”

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Outcomes in child health



A Whole Population Approach: Patient Segments in Child Health

Integrated care is often built around patient pathways. In stratifying children and young people we strongly advocate a 'whole population' approach, where 6 broad patient 'segments' can be identified:

Healthy child	<ul style="list-style-type: none">• <i>Advice & prevention</i> eg: Immunisation / Mental well-being / Healthy eating / Exercise / Dental health
Child with social needs	<ul style="list-style-type: none">• eg: Safeguarding issues / Self-harm / Substance misuse / Complex family & schooling issues / Looked after children
Child with complex health needs	<ul style="list-style-type: none">• eg: Severe neurodisability / Down's syndrome / Multiple food allergies / Child on long-term ventilation / Type 1 diabetes
Child with single long-term condition	<ul style="list-style-type: none">• eg: Depression / Constipation / Type 2 diabetes / Coeliac Disease / Asthma / Eczema / Nephrotic syndrome
Acutely mild-to-moderately unwell child	<ul style="list-style-type: none">• eg: Upper respiratory tract infection / Viral croup / Otitis media / Tonsillitis / Uncomplicated pneumonia
Acutely severely unwell child	<ul style="list-style-type: none">• eg: Trauma / Head injury / Surgical emergency / Meningitis / Sepsis / Drug overdose

Preschool Wheeze

- **wheeze** - musical, high-pitched, expiratory sound associated with increased work of breathing, that can also sometimes be heard in inspiration ¹
- **very common** - about 30% of children during the first 3 years of life
- **clinical phenotypes in young children** - episodic viral wheeze (most common) and multiple trigger wheeze (less common) ²
- as physicians, we fail discussing **environmental prevention with families**
- **is it a long-term condition** – majority of wheezers grow out of the condition but families go through difficult years ³
- annual rate of emergency department visits is **23–42 per 1000** for preschool children with wheeze, compared with less **than 15 per 1000** for those aged above six years old ⁴

¹ *Infantile Wheeze: rethinking dogma* Fernando Maria de Benedictis, Andrew Bush, Arch Dis Child 2017

² *Classification and pharmacological treatment of preschool wheezing: changes since 2008* Brand PL., ERJ 2014

³ *Around the world : preschool wheeze* Makrinioti H. et al., Lancet Resp Med 2017

⁴ *Ducharme FM, Tse SM, Chauhan B. Diagnosis, management, and prognosis of preschool wheeze. Lancet. 2014*

Preschool Wheeze

Preschool wheeze hospital admissions

Oral prednisolone in preschool children with virus-associated wheeze: a prospective, randomised, double-blind, placebo-controlled trial    

S J Foster, M N Cooper, S Oosterhof, M L Borland

	Placebo (n=300)	Prednisolone (n=305)	Unadjusted model coefficient (95% CI)*	p value	Adjusted model coefficient (95% CI)†	p value
Primary outcome						
Length of stay, min	540 (124-971)	370 (121-709)	0.79 (0.64-0.97)	0.0227	0.80 (0.65-0.99)	0.0393
Sensitivity analysis						
Length of stay >4 h	196 (65%)	195 (64%)	0.98 (0.87-1.10)	0.72	1.01 (0.89-1.14)	0.89
Length of stay >7 h	170 (57%)	139 (46%)	0.80 (0.69-0.94)	0.0067	0.82 (0.69-0.96)	0.0166
Length of stay >12 h	115 (38%)	75 (25%)	0.64 (0.50-0.82)	0.0003	0.67 (0.51-0.86)	0.0018

Data are median (IQR) or n (%), unless indicated otherwise. *Model coefficient is either the ratio, for prednisolone relative to placebo, of geometric means (logged continuous variable) from a linear regression model or the relative risk (dichotomous variable) from a log-binomial regression. †Model adjustments include age, personal and family history of atopy, baseline pulmonary score, and presence of virus.

Table 2: Unadjusted and adjusted model outputs for length of stay until ready for discharge (primary outcome) and sensitivity analysis (post-hoc superiority analysis)

Preschool Wheeze

Around the world: preschool wheeze, Lancet Respiratory Medicine, August 2017
Makrinioti H., Klaber R., Watson M.



Designing an outcome measurement tool

During the last month how often did your child cough during their night sleep ?

During the last month how often did you use inhalers for your wheezy child?

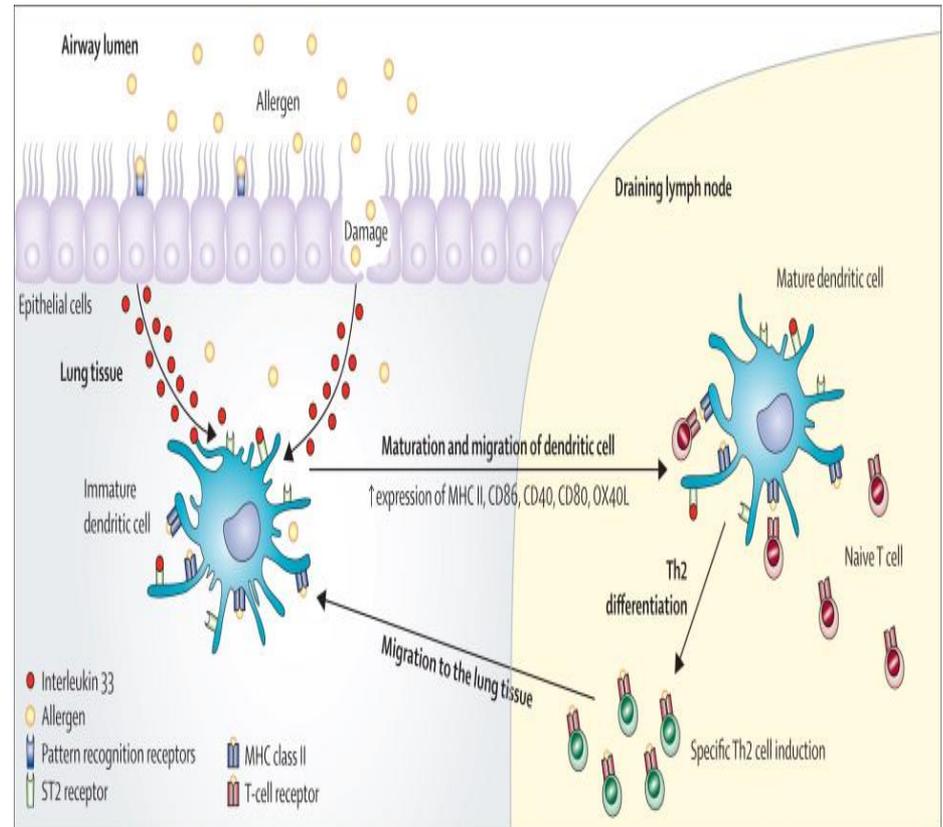
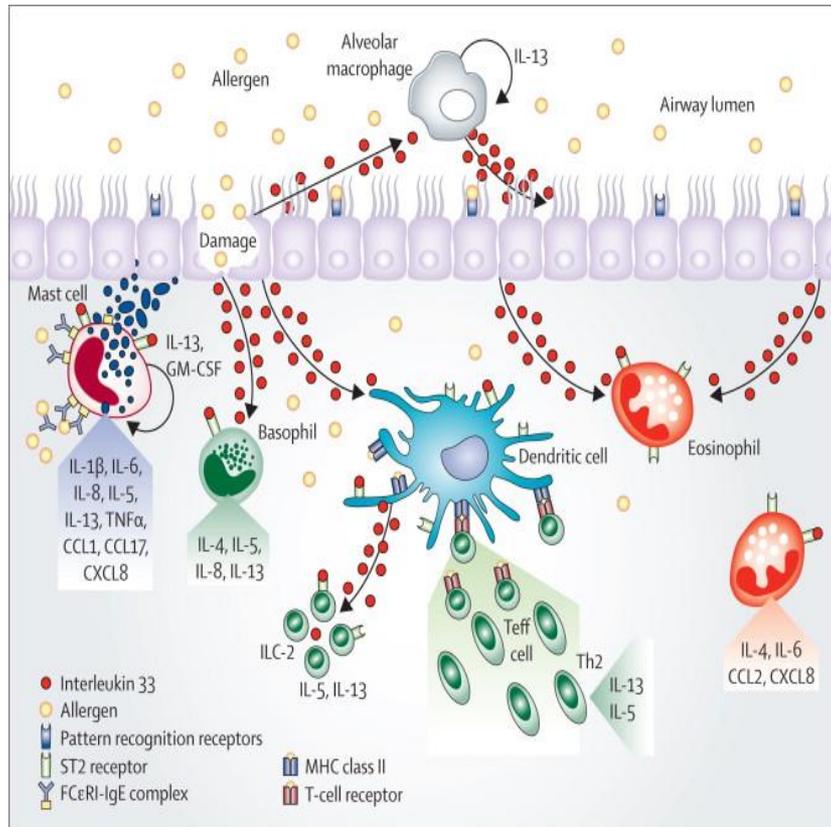
What matters to you ?

How do you cope with your child being in and out of hospital so often?

How do you feel living with a child having this condition?

My design is better than yours

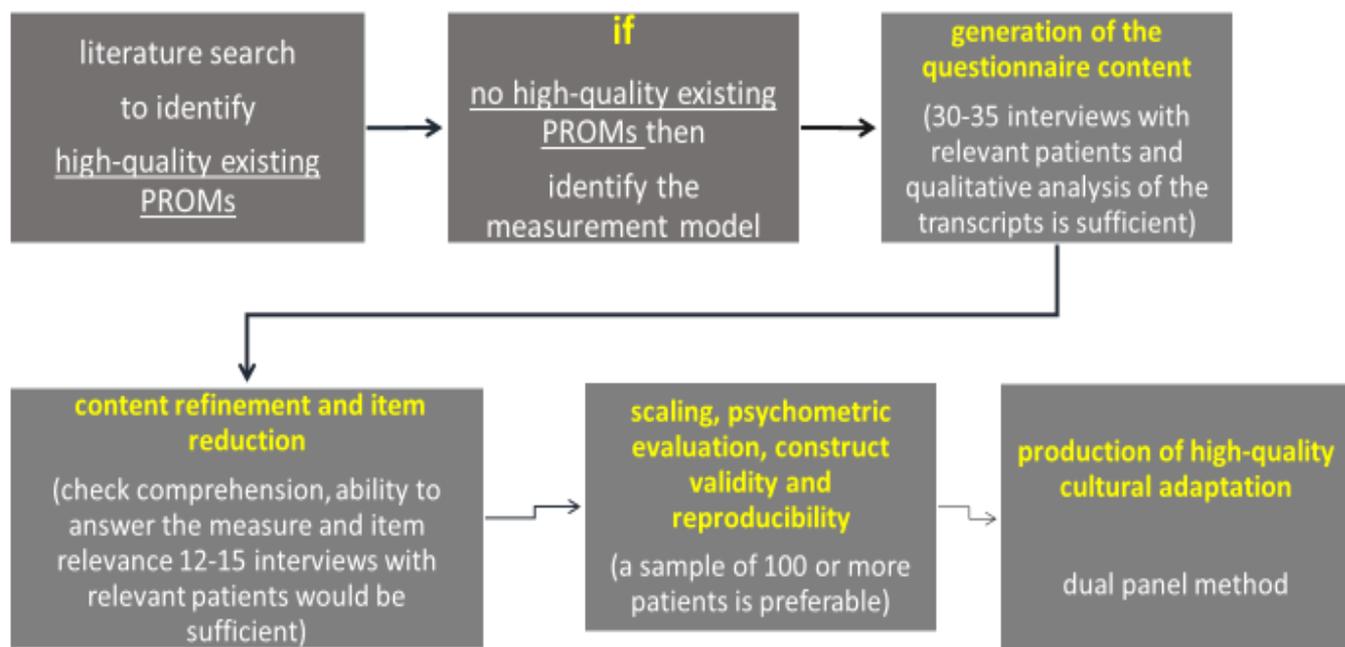
Role of interleukin 33 in respiratory allergy and asthma , Lancet Respiratory Medicine Journal



Dr Heidi Makrinioti, Marie Toussaint, David J Jackson, Ross P Walton, Prof Sebastian L Johnston

My design is better than yours

Development, validation and adaptation of PRO measures

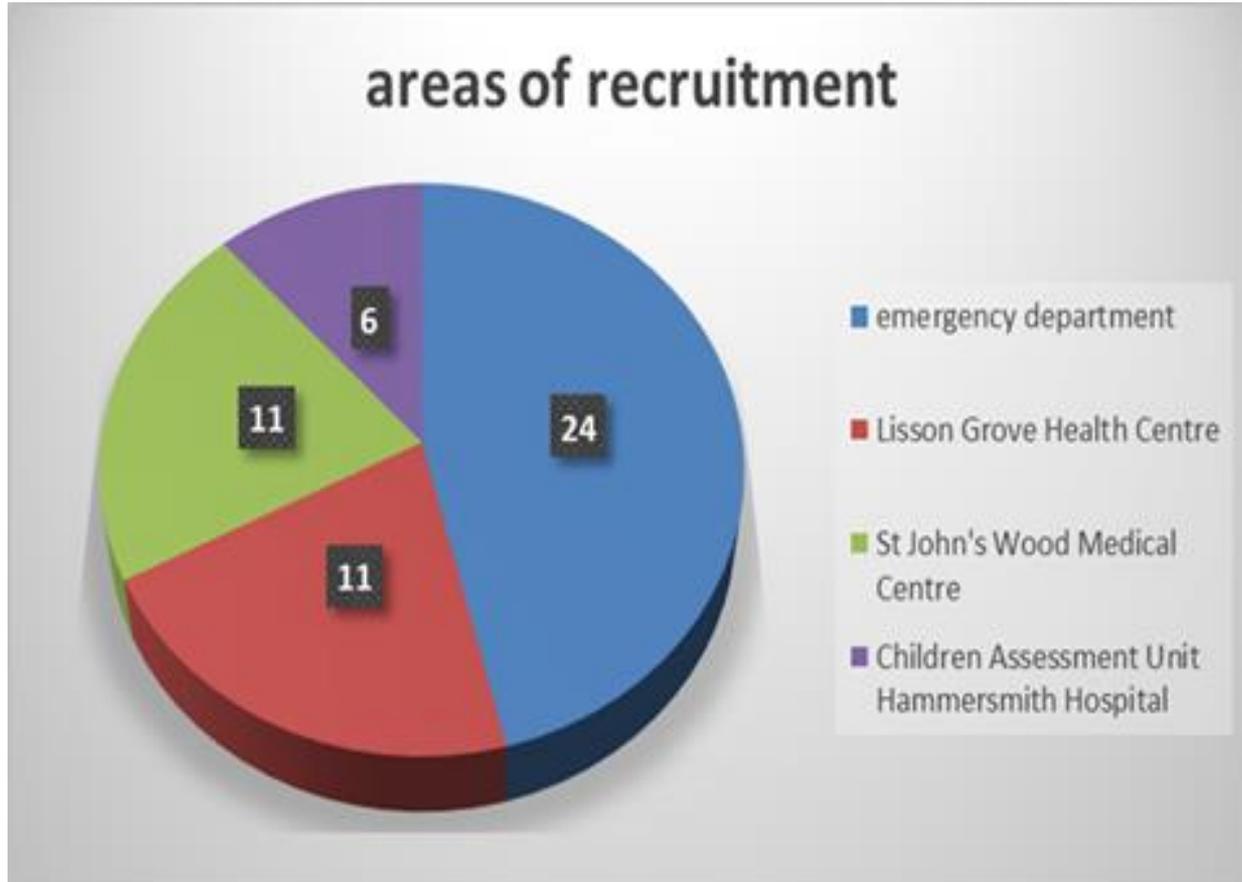


My design is better than yours

 connecting care for children



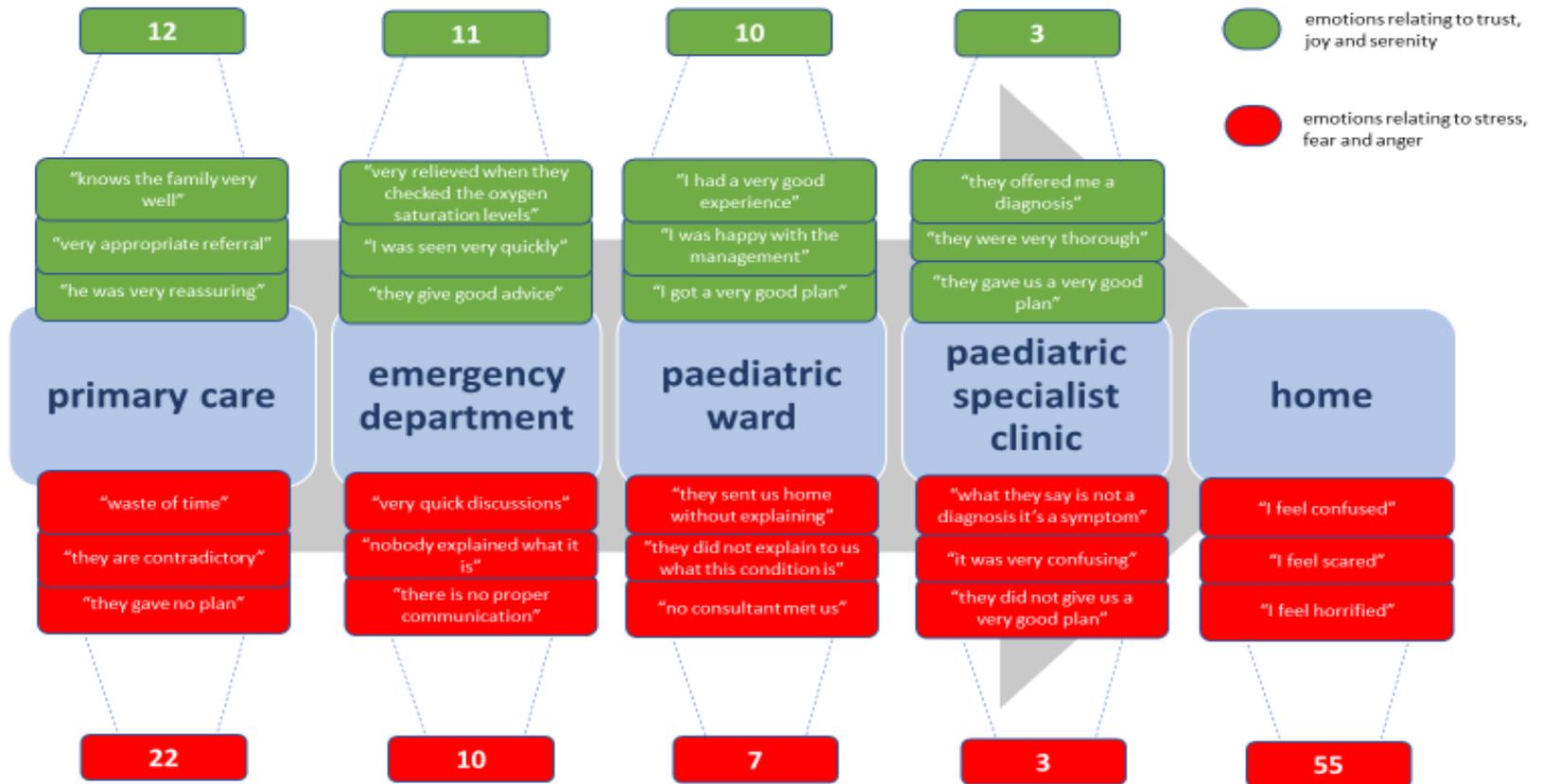
Patient (parent) reported outcomes



How do parents of preschool wheezers feel when they experience healthcare services

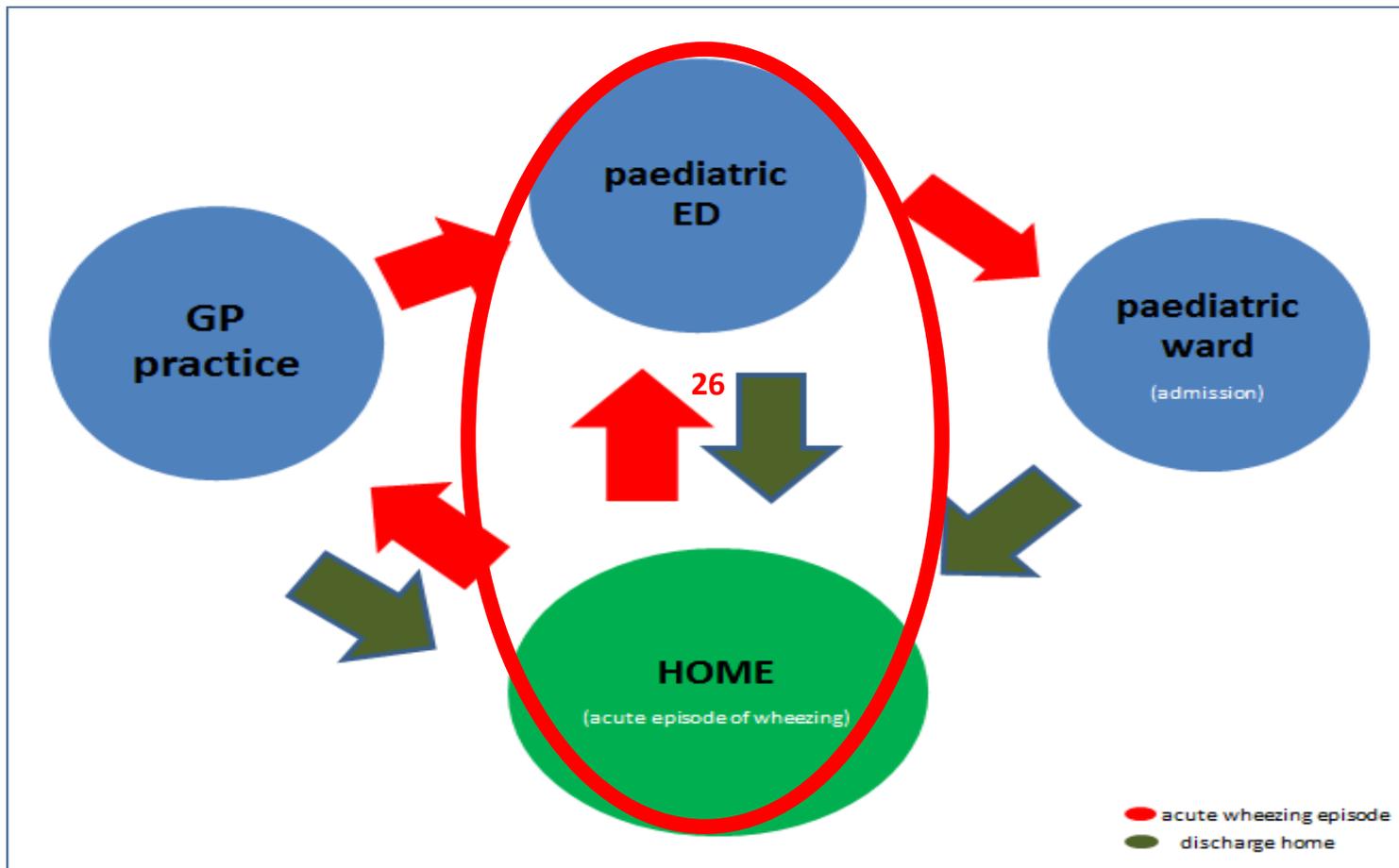


emotional map describing parental feelings



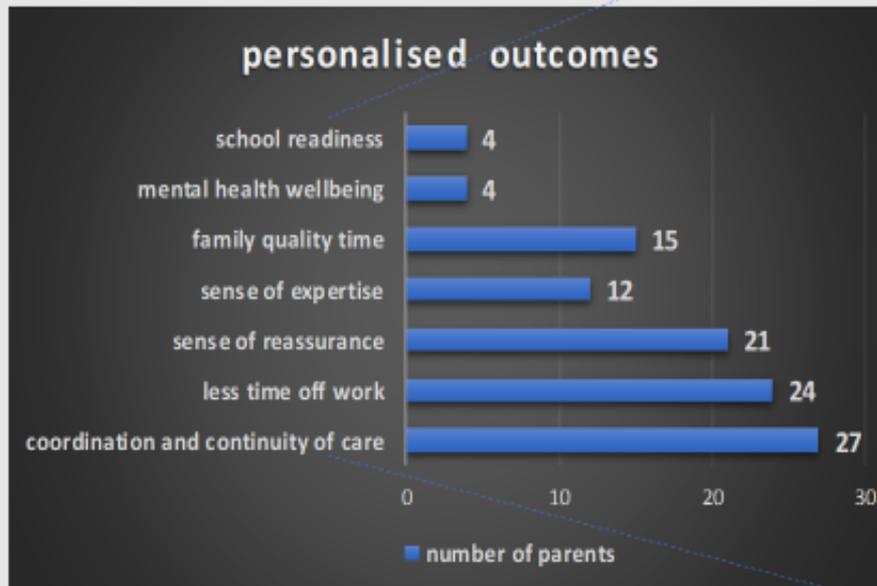
where they seek for help

process map of patient's journey



which are the main outcomes

connecting care for children



"I need to have some time to teach him things – my niece is far more advanced than him"

"I need to maintain my mental health wellbeing – I can't stay calm and I feel always stressed"

"I need to save time and effort and focus on family"

"I need to have a better idea of what this is in order to feel better"

"knowing more about it would provide reassurance"

"I need more time for work, I have no time for education, I need something simple to have at home"

"I need a plan for his management that doesn't change all the time"

Wheeze and me questionnaire

9-item questionnaire that measures

1. incidence of wheeze attacks and use of rescue medications
2. parental/caregiver perception of recurrent wheeze control
3. parental/caregiver perception of effect of recurrent wheeze on family/child quality of life

The challenge

- a variety of instruments measuring outcomes in childhood conditions
- few of them successfully used to provide insightful information around outcomes of research interventions
- couple of them commissioned to be used in bedside

Will we be able to translate **patients' voices into healthcare management tools?**

Will these tools be used **to assess outcomes in population-wide open studies?**